Death without distress? The taboo of suffering in palliative care

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Abstract: Palliative care (PC) names as one of its central aims to prevent and relieve suffering. Following the concept of "total pain", which was first introduced by Cicely Saunders, PC not only focuses on the physical dimension of pain but also addresses the patient's psychological, social, and spiritual suffering. However, the goal to relieve suffering can paradoxically lead to a taboo of suffering and imply adverse consequences. Two scenarios are presented: First, PC providers sometimes might fail their own ambitions. If all other means prove ineffective terminal sedation can still be applied as a last resort, though. However, it may be asked whether sedating a dying patient comes close to eliminating suffering by eliminating the sufferer and hereby resembles physician-assisted suicide (PAS), or euthanasia. As an alternative, PC providers could continue treatment, even if it so far prove unsuccessful. In that case, either futility results or the patient might even suffer from the perpetuated, albeit fruitless interventions. Second, some patients possibly prefer to endure suffering instead of being relieved from it. Hence, they want to forgo the various bio-psycho-socio-spiritual interventions. PC provider's' efforts then lead to paradoxical consequences: Feeling harassed by PC, patients could suffer even more and not less. In both scenarios, suffering is placed under a taboo and is thereby conceptualised as not being tolerable in general. However, to consider suffering essentially unbearable might promote assisted dying not only on an individual but also on a societal level insofar as unbearable suffering is considered a criterion for euthanasia or PAS.

DOI: https://doi.org/10.1007/s11019-019-09921-7

Uncorrected draft

Streeck, Nina (2019): Death without distress? The taboo of suffering in palliative care

In: Medicine, Health Care and Philosophy, doi: 10.1007/s11019-019-09921-7
http://link.springer.com/article/10.1007/s11019-019-09921-7

Abstract
Palliative care (PC) names as one of its central aims to prevent and relieve suffering. Following the concept of "total pain", which was first introduced by Cicely Saunders, PC not only focuses on the physical dimension of pain but also addresses the patient's psychological, social, and spiritual suffering. However, the goal to relieve suffering can paradoxically lead to a taboo of suffering and imply adverse consequences. Two scenarios are presented: First, PC providers sometimes might fail their own ambitions. If all other means prove ineffective terminal sedation can still be applied as a last resort, though. However, it may be asked whether sedating a dying patient comes close to eliminating suffering by eliminating the sufferer and hereby resembles physician-assisted suicide (PAS), or euthanasia. As an alternative, PC providers could continue treatment, even if it so far prove unsuccessful. In that case, either futility results or the patient might even suffer from the perpetuated, albeit fruitless interventions. Second, some patients possibly prefer to endure suffering instead of being relieved from it. Hence, they want to forgo the various bio-psycho-socio-spiritual interventions. PC provider's' efforts then lead to paradoxical consequences: Feeling harassed by PC, patients could suffer even more and not less. In both scenarios, suffering is placed under a taboo and is thereby conceptualised as not being tolerable in general. However, to consider suffering essentially unbearable might promote assisted dying not only on an individual but also on a societal level insofar as unbearable suffering is considered a criterion for euthanasia or PAS.

Introduction

There is a consensus within medicine that suffering should be eliminated whenever possible. Palliative care (PC), particularly, has drawn attention to forms of suffering that are not primarily bodily in nature. Following a holistic concept of "total pain", which was first introduced by Cicely Saunders in the 1960's, PC not only focuses on the physical dimension of pain but also addresses the dying patient's psychological, social, and spiritual suffering.

Although it seems reasonable for PC to offer such comprehensive care, especially to patients at the end of their lives, there is a downside to this endeavour. As I will argue in this paper, the goal of PC to relieve all kinds of pain – physical, psychological, social, spiritual – might lead to a taboo of suffering. Interpreting each and every suffering as a signal to take action against it clearly implies the message that suffering should be avoided at all costs. Whenever the patient's suffering proves entirely intractable, for whatever reason, PC professionals can only interpret it as a failure: They did not manage to provide their patient an end-of-life if not free, at least partly relieved from suffering. Suffering, hence, is placed under a taboo insofar as it is viewed as totally unacceptable and should not be displayed by anyone.

However, placing suffering under a taboo might entail problematic consequences. I will draw on two possible outcomes. First, it could promote assisted dying[1] once PC fails its own ambition to alleviate suffering. If a patient's suffering persists despite PC's bio-psycho-socio-spiritual offerings of care, seemingly only one alternative remains to release him from his distress: death. In that case, suffering is eliminated by eliminating the sufferer. Hence, as an imperative, the prevention of suffering might evoke a climate of approval of assisted dying. On the other hand, PC providers could nevertheless aim at success in relieving a person's suffering although they so far failed. However, the prolonged efforts could have a detrimental effect and lead to further distress for the patient. He might feel under pressure to get better and develop an even greater disposition to suffer when realising that he cannot meet his caregivers' expectations. Similar paradoxical consequences might result if PC providers ignore a patient's wish to endure his suffering. It can be thought of several potential reasons for such an attitude towards suffering that I will elaborate on. Such a person might get the impression that his needs and wishes are not properly appreciated if his caregivers want him to become less distressed. He, too, might even feel urged to submit to PC although he does not wish for receiving therapy or any other treatment against his suffering. It can cause distress if he believes that his caregivers expect him to approve of the action taken. He then might suffer from feeling under pressure to call upon PC's interventions. Also in that case, his initial suffering possibly even increases.

In the following, I first present how suffering is conceptualised within the field of PC. For that purpose I mainly refer to the depiction of suffering in the Oxford Textbook of Palliative Medicine. On this basis I consider two scenarios of misplaced endeavours to relieve suffering. First, PC providers sometimes might fail to alleviate suffering by means of bio-psycho-socio-spiritual interventions. In that case two options remain: Either terminal sedation is applied as a last resort or treatment is continued, hoping that it will prove successful later on. As I will argue, both alternatives show downsides. Considering the similarities of terminal sedation and euthanasia I discuss whether the former comes close to eliminating suffering by eliminating the sufferer. The continuation of treatment, on the other hand, could turn out futile permanently and, above that, put pressure on the patient and let him suffer even more. Similar consequences result in the second scenario. Some patients possibly prefer to endure suffering instead of being relieved from it. If PC providers nevertheless try to apply their bio-psycho-socio-spiritual care patients might feel harassed so that their suffering even increases. As becomes obvious, the self-imposed imperative to alleviate suffering at all cost might lead to placing it under a taboo. If this happens the impression is created that suffering per se cannot be endured. Considering the fact that "unbearable suffering" counts as a criterion for assisted dying in some countries it seems as if tabooing suffering can promote assisted death.[2]

[1] Whenever I speak of assisted dying I am referring to physician-assisted suicide (PAS) and euthanasia without further differentiation. In both cases, the physician's intention is to help hastening death if requested by the patient. However, in PAS he helps a person to kill herself while in euthanasia he himself kills the person by injection of a lethal drug.

[2] Admittedly, my hypothesis abides empirical evidence. However, the aim of my paper merely is to draw attention to possible unwanted consequences that come along with a guiding principle of PC. Thus, my critique primarily applies to an ideal and not to practice. I am not claiming that no physician is aware of the limits of his professional conduct concerning the alleviation of suffering. Instead, my suggestion consists in constantly reflecting upon certain ideals of PC so that the – undoubtedly already strong – respect for autonomy can even increase.

The concept of suffering within PC

According to the WHO, PC aims to improve a patient's quality of life "through the prevention and relief of suffering" (WHO 2002). The definition makes clear that alleviating suffering is considered as necessarily enhancing a person's wellbeing and contributing to a good end-of-life. Both, the improvement of a person's quality of life and the relief of suffering are unanimously regarded as central aims of PC although differences in the definition of PC persist (Pastrana et al. 2008).

That PC offers support for those suffering at the end-of-life goes back to its very first beginnings. The emergence of hospice care and, later on, of PC arose from a critique of the neglect of dying people within in medical system. Among the developments that led to innovations in the care for the dying was the recognition in the 1950's of the interdependence of physical and mental distress that was taken up by Cicely Saunders, the founder of the modern hospice movement (Clark 2002). Since she felt that medicine had abandoned the dying Saunders opened the first modern hospice, St. Christopher's, in London in 1967 which makes her one of the main figures in the early development of PC. She coined the term "total pain" defining it as a "complex of physical, emotional, social, and spiritual elements" (Saunders 1996). In her writings, Saunders mentions a dialogue with one of her patients that she describes as crucial for her understanding of pain in the terminally ill: "[…] it seems that all of me is wrong" (Saunders 1964), the patient complained, describing various symptoms that Saunders interpreted as "mental as well as physical distress, […] social problems and […] spiritual need for security" (ibid.).

Hereby highlighting the totality of pain she wanted to draw attention to the fact that the sufferings of dying persons reached beyond their physical maladies. Her emphasis on the multidimensionality of pain at the end of life gained wide influence within the hospice movement whereas "total pain" became one of its most powerful concepts (Clark 1999). Treating the bio-psycho-socio-spiritual distress of the dying meant to apply holistic care or, as the European Association of Palliative Care (EAPC) later on put it, "active, total care" (EAPC 2018).

St. Christopher's hospice soon became famous. Visitors drew inspiration from Saunders' work and themselves found institutions for the care of the terminally ill in their own countries, among them the Canadian surgeon Balfour Mount. He was the first to use the term "palliative care" in 1973, referring to the Latin phrase "pallium" (cloak). While the hospice movement operated outside of the established health services Mount located his palliative care unit within the Royal Victoria Hospital in Montreal. What began as criticism of standards and practices of medical end-of-life care gradually turned into a sub-specialty of mainstream medicine (Woods 2007).

PC, in accordance with Saunders' concept of "total pain", adopted the holistic approach and took up the cause of meeting the totality of pain experienced by dying patients (Bishop 2011). However, the integration of PC into mainstream medicine soon came to be seen both as an opportunity and as a threat. As PC got the chance to introduce its principles and philosophy of care to the healthcare system it was in danger to jeopardize its ideals and be 'colonised' (Woods 2007). Already in the 1990's the increasing routinization and medicalisation of hospice engendered criticism (James and Field 1992). The debate continues, and PC's treatment of suffering can be seen as an example of the

manifestation of the tension between the integration of PC into the medical system and the desire to set a counterpoint to regular medical practice.

The relief of suffering is considered a central aim of medicine, especially if cure is not possible. According to the Oxford Textbook of Palliative Medicine its recognition lies "at the heart of the philosophy, science, and practice of palliative medicine" (Cherny 2009). Although the definition of PC as well as of its scope and tasks vary there seems to be a consent that PC's main goal is to enhance the patient's quality of life and to relieve suffering whereby an improved quality of life is believed to be achieved by the latter (Pastrana et al. 2008).

Drawing on the definition of suffering as "an aversive experience characterized by the perception of personal distress that is generated by adverse factors that undermine quality of life" Cherny, in the Oxford Textbook, identifies four areas of potential distress that are amenable for therapeutic interventions: 1) Pain and other physical symptoms, e.g. nausea, fatigue, vomiting, dyspnoea, constipation, 2) psychological factors, such as anxiety, depression, confusion, insomnia, as well as factors that might adversely influence these disorders, e.g. physical symptoms, feelings of hopelessness, lack of perceived support, strained relationships, 3) existential (or spiritual) issues, e.g. the view that life may be without meaning, death anxiety, disappointment, religious issues, and 4) family and caregiver distress, resulting from the anticipated loss, from being witness to the patient's distress, or from the burden of care. Concerning the last point, Cherny discusses additional issues that primarily affect family and healthcare professionals. Above that, he emphasises the interrelatedness of the patient's, his family's and the caregiver's distress. Eventually, he ends up with a long list of potential factors of suffering. What is thus needed, given the aim to alleviate suffering, is the "careful case assessment, identification of care needs, formulation of a multidisciplinary therapeutic intervention to address those needs, and the provision of ongoing monitoring with readiness to re-evaluate the care plan" (Cherny 2009).

Applying state-of-the-art total care for total pain needs elaborate professional expertise. Central to the PC provider's endeavours to alleviate suffering is the evaluation and assessment of the patients, the families and caregiver distress, by looking into their biological, psychological, social, financial and spiritual life. Cherny proposes a list of questions that should be addressed to be capable of turning up with a detailed care plan for all dimensions of suffering. To be able to offer holistic care a multidisciplinary approach, due to the multidimensionality of suffering, is crucial.

However, in recent years, PC has engendered criticism for its total care approach, echoing the earlier concerns about an increasing routinization and medicalisation (Bishop 2011, Floriani and Schramm 2012, Randall and Downie 2006, Woods 2007). Randall and Downie, in their analysis and critique of the philosophy of PC, question whether the "assessments, questionnaires, counselling, and measurement scales […] can also be seen as a kind of harassment at the end of life" (Randall and Downie 2006). Bishop goes even further in calling total care "oppressive" (Bishop 2011: 277). I will later come back to this point. To sum up for now, PC evidently advocates a broad concept of suffering. It not only includes physical, psychological, existential/spiritual and social issues but also takes into account family and caregiver distress. For all of these potential sources of suffering PC providers wish to offer support. As I will argue in the next section, what comes as a tremendous

aspiration with a fair risk of failure also implies the possibility of paradoxical consequences: It might lead to even greater suffering.

Misplaced endeavours to relieve suffering: Two scenarios.

In the following, I consider two scenarios of misplaced endeavours to alleviate suffering.

Scenario 1: PC's failing ambitions

In some cases PC professionals fail in their attempt to prevent or relieve a patient's suffering. Facing death certain patients experience lasting feelings of loss, grief, loneliness, and other negative emotional states that prove resistant against treatment and therapies. Efforts to improve the patient's quality of life by offering him bio-psycho-socio-spiritual support just lack the desired effect. Although PC professionals try their best, in such a case the patient persistently does not feel better and less distressed.

Apparently, whenever the alleviation of suffering by bio-psycho-socio-spiritual support fails two options remain if PC providers want to adhere to their self-imposed goal to relieve suffering, namely a) terminal sedation or b) continued efforts of treatment:

a) Terminally sedating the patient

If the relief of suffering by therapeutic measures fails PC still has to offer a way to silence suffering, namely the option of palliative sedation as a last resort. As the framework of the European Association of Palliative Care indicates palliative sedation might be applied if the patient's suffering becomes unbearable:

"Therapeutic (or palliative) sedation in the context of palliative medicine is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering"(Cherny et al. 2009).

There is no doubt that palliative sedation puts an end to suffering. Deep continuous sedation until death[3] constitutes a special case in that context. Since it is not meant to be withdrawn it can be argued that the elimination of suffering by such means comes close to eliminating the sufferer, especially as the patient's consciousness is permanently cut off (Bozzaro 2015). Not surprisingly, controversies about the differences and similarities of sedation and euthanasia accompanied the development of both practices from the start, and they still continue.[4] Both end-of-life measures not

[3] In the following I either speak of deep continuous sedation until death or use the term "terminal sedation" synonymously. However, PC offers other forms of sedation. The broader concept of "palliative sedation" describes the application of suitable drugs to – partly or completely – reduce a patient's consciousness in order to alleviate his suffering. The strongest form, terminal sedation, is only applied as a last resort if other means do not suffice and the patient's symptoms still prove refractory (Bozzaro 2015).

[4] I do not want to elaborate in detail on the long-lasting controversy about the differences and similarities of euthanasia and terminal sedation. For an overview of the pros and cons cf. ten Have/Welie 2014.

only effectively annihilate a person's suffering but resemble each other in that the patient receives an injection, passes out and remains unconscious until death. Occasionally (and highly contested), sedation is deemed nothing else than "slow euthanasia" (Billings/Block 1996) or "equivalent to physician-assisted suicide/euthanasia" (Lipuma 2013). At least, terminal sedation can be said to have an "unclear border with euthanasia" as it is "more an eradication of symptoms" (Materstvedt and Bossard 2009a). However, it must be noted that the intention of sedating the patient is to free him from suffering and not to kill him although it is intended to leave him in a state of unconsciousness.

Against this backdrop and despite the differences, the question arises whether PC promotes assisted dying by setting the prevention and relief of suffering as its central goal. Alongside terminal sedation, assisted suicide or euthanasia effectively annihilates a person's suffering, too. Both PC providers and proponents of assisted dying share the aversion against suffering and attach paramount importance to its alleviation (Hurst and Mauron 2006). Whether PC and assisted dying can be regarded as alternative means to eliminate suffering, such that successful PC leads to a decrease in requests for assisted dying, remains controversial.

Nevertheless, assuming that PC (disregarding terminal sedation) sometimes fails to make suffering tolerable for the patient turning to assisted dying might be an obvious and secure way to avoid further suffering (Hofmann 2017). Or, as Bishop put it, should PC fail, "one always has hemlock to cause death" (Bishop 2011: 278). However, choosing euthanasia or physician-assisted suicide (PAS) as an alternative to PC clearly runs contrary to PC's traditional goal to prevent patients from taking that step. Cicely Saunders was a strong opponent of euthanasia and frequently stressed better care for the dying as an antidote (Clark 2007). Although many PC professionals still take a stance against assisted dying meanwhile some of them either do not totally reject it or even want to embed euthanasia in PC, as it is already common practice in Belgium (Bernheim and Raus 2017). However, the Oxford Textbook of Palliative Medicine still sets out the warning that an inadequate relief of suffering might lead patients, their families, and professional healthcare providers to turn to euthanasia or PAS (Cherny 2009).

I do not want to suggest that PC is on a slippery slope towards euthanasia, though. Rather, I want to question whether terminal sedation and assisted dying can appear as equally appropriate means to eliminate suffering. Considering the resemblance of the two approaches without ignoring their differences this could clearly be the case if ending suffering ranks as paramount goal of end-of-life care.

b) Continuing (futile) treatment

Besides the option of terminal sedation there seems to be an alternative to remain faithful to the aim of alleviating suffering although all efforts, until then, did not entail the desired effect: PC professionals might nonetheless apply their bio-psycho-socio-spiritual program of care further on, hoping that sooner or later one of their treatments will relieve their patient from suffering. That touches the question whether PC can ever become futile. As Mastertvedt and Bosshard argue, this is not the case because PC can always offer relief, at least terminal sedation as a last resort (Matersvedt and Bosshard 2009b). However, this perspective implies that other palliative means very

well can be futile. From an ethical point of view, futility lacks a medical rationale and can clearly be rejected.

Besides being futile it might lead to further unwanted consequences to continue bio-psycho-socio-spiritual treatment that obviously does not lead to success. If a patient realises how strongly his caregivers make an effort he might want to be a "good patient" who responds to the painstaking care of the PC professionals. He might even feel obliged to show gratitude and express feelings of wellbeing although he still suffers. Possibly, his suffering even increases. Unintentionally, the patient's caregivers might lead him to believe that he is not supposed to suffer any longer or at least that he should feel partially less distressed. In that case, he maybe suffers from the fact that he cannot fulfil his caregiver's expectations. Instead of suffering less, as the PC professionals hope for, he suffers even more.

Not coincidental, Cassel identified medical interventions themselves as a potential source of suffering: "Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself" (Cassel 1982). In that sense, the depicted conception in the Oxford Textbook of Palliative Medicine – that it is crucial for PC provider to conduct a meticulous and detailed assessment of a patient's suffering and subsequently offer him comprehensive therapeutic interventions – puts a different complexion on the endeavour to relieve suffering. In their wish to gather comprehensive information about the patient's condition PC providers might even be inclined to ask intrusive questions (Randall and Downie 2006). Thereby, already the assessment can prove a source of suffering, doing more harm than good to the patient. As Jeffrey Bishop argues, PC's total care might even be experienced as "totalizing care, indeed, totalitarian care" (Bishop 2011).

Second scenario: Insufficient consideration of patients' wishes

A similar effect might occur if the patient does not want his suffering to vanish but prefers to endure it. One can think of several reasons for such a wish. Jukka Varelius discusses three points why under certain circumstances suffering could be considered a part of dying well: If the patient's distress was alleviated it might a) withhold him from taking care of practical end-of-life issues, b) deprive him of the opportunity to find meaning in and for his existence, and c) detach him from reality (Varelius 2018). The arguments Varelius presents go as follows: The alleviation of suffering by stopping vital treatment, by sedation, or by ending one's life (via PAS or euthanasia) clearly annihilates the possibility to arrange one's affairs, for example to finalize an important project or to reconsider one's will (a). On the other hand, as Varelius objects, it might be the case that only PC treatments like talk therapies or spiritual counselling put the patient in the position to do so. Furthermore, suffering in some cases possibly results in personal progress (b). Drawing on psychological studies about posttraumatic growth Varelius argues that traumatic experiences such as a terminal illness can confront an individual with questions about the meaning of one's life. As reflection upon these issues might otherwise remain undone it provides the patient with the opportunity to find significance in his existence in a deeper sense. Lastly, one could argue that being in touch with reality and therefore acknowledging one's imminent death is better than living in a state of denial (c). Being in contact

with reality has a substantial intrinsic value, or so the argument goes. Den Hartogh, too, stresses the latter reason to appraise end-of-life distress a part of dying well (Den Hartogh 2017). Nearing death, he argues, it can be an appropriate reaction to experience grief, sadness, and other negative emotional states. Trying to inhibit such feelings would mean to wrongfully consider them as a symptom or a pathology that has to be fought. Above that, the patient would be left in a "world of illusion" (Den Hartogh 2017) while not acknowledging that his life will end soon.

However, Varelius questions whether the arguments a) to c) offer ground enough to promote suffering as a part of dying well and therefore abstain from PC interventions. Particularly, this applies if PC is able to alleviate a patient's suffering without depriving him of the opportunity to take care of end-of-life issues, to ask questions about the meaning of his existence, or to keep in contact with reality. Certain PC means such as antidepressants, talk therapies or spiritual counselling (and in some cases also the knowledge to have access to life-shortening methods such as euthanasia or PAS) may even improve a patient's ability to reach these goals. Thus, concludes Varelius, it can be doubted whether suffering at the end of life makes for a better death. Whenever a patient may accomplish the mentioned activities free from suffering, or enduring suffering serves these aims as well as its alleviation, one would obviously choose the latter as suffering does not convey any intrinsic value.

My argument, however, draws on a different starting point. I do not follow a certain *objective* idea of dying well as it is implied in the above discussion. Not only is living in contact with reality (c) conceptualised as having a substantial intrinsic value in Varelius' argument but also are the other two points. Both taking care of one's end-of-life issues (a) and asking question about the meaning of life (b) are regarded as objective constituents of dying well. However, it is easily conceivable that a person facing her imminent death prefers not to attend to practical end-of-life matters, such as revising his will or arranging his own funeral, and not to address questions of meaning.

Therefore, I assume a *subjective* idea of dying well instead, i.e. the patient himself determines what he considers important to have a good death. Some patients conceivably might take a different stance towards suffering than wishing to be relieved from it. Although they did not want to undergo suffering in the first place, when it occurred due to their imminent death and their terminal illness, they thereafter possibly prefer to endure it rather than dispose of it.

The reasons for such an attitude can be manifold, starting with the points a) to c) which Varelius mentions. Allan Kellehear discusses three additional opportunities that "mortal suffering", as he calls it, offers the dying person: a reality check, a psychological check, and a moral test (Kellehear 2014). Whereas Varelius goes so far to consider suffering a potential part of dying well Kellehear takes a more cautious position. Suffering, as he argues, poses challenges on the dying individual. First, he finds himself compelled to re-examine his assumptions about life, such as love, fairness, his priorities and values etc., which gives him the opportunity to develop a new view of reality (reality check). Second, and similar, suffering resembles a journey into uncharted psychological territory. The new experiences facing death will change who one is and what is important to him (psychological check). Third, suffering calls upon a person's response such that he can choose an attitude towards suffering. Enduring suffering, or so Kellehear argues, comes as a moral test: He who accepts his fate can find meaning and thus obtain his dignity. Other than Varelius, Kellehear does not discuss the question

whether the alleviation of suffering should be abandoned to allow a person for undergoing the three tests. However, he reflects potential reasons why a dying person could decide to endure suffering. What unites Varelius', DenHartogh and Kellehear is their concern to attach meaning to the seemingly meaningless experiences of suffering. In doing so, they continue long-lived traditions of philosophical and theological approaches to deal with suffering, reaching back to the days of Job and continuing in the work of philosophers such as Kierkegaard, Nietzsche, Scheler, Heidegger, or Simone Weil (Svenaeus 2018).

Generally speaking, an individual might just consider suffering an inevitable constituent of life that he chooses to tolerate. If a person's physical and cognitive abilities decline due to her imminent death it is surely not unusual that feelings of loss, grief, or sadness occur. The person herself might regard these emotions as an appropriate response to her experiences. Reacting in such a way to adverse life events possibly reflects her attitude towards life and even expresses her personality. Applying PC to relieve this person from suffering would run contrary to her attitude, to her idea of a good life (and death), and to her moral values. Suffering, in that sense, does not entail an intrinsic worth but it can deploy some kind of value for the dying individual. Caring for such a person, PC professionals are mistaken if they believe that the alleviation of suffering necessarily improves the patient's quality of life, as the WHO definition suggests. To endure suffering, when it occurs at the end of life, reflects a different concept of quality of life, or the good life. In the same vein runs the possibility that PC providers assume that the patient has unmet needs although he himself is not aware of these needs (Randall and Downie 2014).

Considering this case the same unwanted consequences might result as discussed above (scenario 1b): In trying to alleviate a patient's suffering PC professionals possibly even augment it. Although the patient certainly could reject PC at any time it already might put some pressure on him just to receive the offer of bio-psycho-social-care that he does not wish to utilise. Especially, this holds true if one considers the vulnerability of a dying individual. In the face of his imminent death he might not feel strong enough to decline what he possibly perceives as demands of his caregivers. On the contrary, he could feel inclined to pretend certain needs, wanting to be perceived as a "normal" patient. Above that, if he gets the impression that his caregivers pathologize his suffering and assess it as a treatable condition he could be prone to accept PC although it just causes further distress (Hofmann 2017). That might happen if his caregivers assume that his reaction to his illness and to his imminent death results from some kind of psychological disorder and represents an inappropriate response to the situation whereas it has to be treated as a pathological condition. Even if they were right it could be doubted whether an end-of-life therapy addressing these issues necessarily does any good, especially as emotions such as grief, sadness, or anxiety can be considered adequate facing death (Randall and Downie 2014). Even if PC providers only cautiously suggest to accomplish certain treatments and therapies they unwillingly might lead their patient to believe that he should accept their support. If he is dependent on care, treatment, or any other kind of help he might feel obliged to be a "good patient" that does not refuse his caregiver's endeavours (Broom 2015). In short, the patient could feel overchallenged and be unable to cope with the assumed demand.

To this context belongs the idea that it can help those who suffer to find meaning in their experience (Cassell 1998). Although not necessarily conceptualised as a relief from suffering in the narrower

sense meaning-making often is considered a worthwhile coping strategy at the end of life, especially in the field of spiritual care (McClement 2009, Wein and Baider 2009).[5] Even if many patients benefit from the quest for meaning and long for support accordingly this might not be true for everyone. To endure suffering can also imply to endure its meaninglessness. Susan Wendell, for example, though not at the end of life but suffering from chronic fatigue syndrome, which involves chronic pain, speaks of the "myth of control" that shows itself in medicine's futile endeavours to fully control the human body and, above that, in reaching out to the realm of the psychological and existential. Wendell, refusing to find meaning in her experience, chooses to remind herself that "the pain is meaningless" (Wendell 1996).

In cases like that, an individual's initial suffering is not alleviated but, rather the opposite, the felt pressure even might add to it. According to Cassel's definition, suffering can occur if a person's integrity is threatened (Cassel 1991). It can easily be imagined that a patient misses the recognition of his identity if his wish to take a certain stance towards his illness is not respected properly. Although the influence of PC professionals offering their support should not be overestimated, the patient, given his vulnerable position, might feel distressed while fearing his integrity being threatened. Cassel, in his seminal book, mentions how a person's integrity depends on the "wholeness of the web of relationships with self and others" which implicates that inattentive care can contribute to her suffering. Hence, not only can medical care reduce the negative impact of sickness but it can also be responsible for an increase of suffering.

Further adverse consequences

So far, I have discussed how PC's goal to alleviate suffering directly can affect an individual patient. I elaborated on two possible consequences: First, if PC fails its own ambition and cannot relieve a patient's suffering it might lead either to the last resort of terminal sedation or even assisted dying or to further, eventually futile, attempts to alleviate suffering that only cause greater distress. Second, if PC professionals, possibly unintended, do not respect some patients' wishes to endure their suffering but continuously try to employ their bio-psycho-socio-spiritual program of care they also might be responsible for additional suffering.

Beyond that, there are further adverse consequences of PC's self-imposed imperative to alleviate suffering. Not only does the PC approach neglect the fact that some patients possibly prefer to bear their suffering in the face of death due to a certain attitude towards life. It also suggests that to endure suffering is not an option at all but that a patient's distress has to be fought at any means. Therefore, the perceived suffering of a patient is taken as a signal to apply treatment, therapies, or counselling in each and every case. Suffering, in that way, is placed under a taboo.

[5] However, spiritual care cannot be reduced to support in a quest for meaning. So far, there is no generally accepted conceptualisation of spirituality, and several concepts of spiritual care exist. In 2009, a Consensus Conference reached the following definition: „Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred" (Puchalski et al. 2009). Correspondingly, a broad range of spiritual health interventions exists.

Tabooing suffering entails consequences that reach beyond the implications for the individual patient. To consider counteracting the one and only means to deal with suffering implies that the latter *per se* is regarded unbearable. That notion not only informs the daily practice of PC professionals but also affects PC's public representation and perception whereby it influences widespread beliefs about the last phase of life.

Against the backdrop of recent practices of euthanasia and PAS, especially in the Netherlands, Belgium and Switzerland, the taboo of suffering yields some interesting questions. Both in the Netherlands and in Belgium "unbearable suffering" is regarded a central criterion for granting euthanasia (Dees et al. 2010). In Switzerland, the Swiss Academy of Medical Sciences (SAMS) recently adopted new guidelines that mention "intolerable suffering due to symptoms of illness and/or functional limitations" as a requirement for the physician to perform assisted suicide (SAMS 2018).[6]

If PC follows the imperative to alleviate suffering at all cost and thereby conceptualises it as inherently unbearable, the question arises whether PC promotes euthanasia and PAS not only on an individual but also on a societal level. It cannot be ruled out that PC's idea of an inherent intolerability of suffering increasingly gains acceptance. If this happens it may well be that experiences of suffering immediately provoke the thought to evade them by death.

Only on first sight this might come as a surprise. Although often regarded as fundamentally opposite PC providers and advocates of assisted dying share some common goals (Hurst and Mauron 2006). The aversion of suffering is one of them. While PC, from its very first beginnings, aimed to target the patient's "total pain" advocates of AS argued with the notion of intractable suffering as a legitimate reason to hasten death. In any case, suffering is conceptualised as an evil, with no positive value whatsoever, so that not even different *individual* attitudes toward suffering are taken into account.

Conclusion

As I tried to show PC's self-imposed imperative to alleviate suffering as to improve a patient's quality of live leads to paradoxical consequences. I first discussed the scenario that PC providers fail in relieving their patient's suffering by offering a bio-psycho-socio-spiritual program of care. What remains as a last resort, then, is terminally sedating the patient. Considering the resemblance to euthanasia I posed the question whether the desire to eliminate suffering under certain circumstances could result in the elimination of the sufferer. Although, in the case of terminal sedation, the death of the patient is not intended his suffering is ultimately eradicated as is the suffering of the euthanised person (concerning the latter, at once with the person herself). However, if PC providers want to stay true to their paramount goal of alleviating suffering but do not want to turn to terminal sedation they might continue in applying bio-psycho-socio-spiritual treatment, therapies, and counselling although their efforts so far were not crowned with success. Not only results futile treatment but also the perpetuated effort might cause further distress for the patient.

[6] The medical association Foederatio Medicorum Helveticorum (FMH) usually includes SAMS guidelines in their code of conduct. However, in this particular case, FMH refused to do so, arguing the criterion of "untolerable suffering" was too vague. Hence, the old guidelines from 2004 still apply.

In the second scenario, I discussed similar paradoxical consequences. Some persons, for different reasons, possibly do not wish to be relieved from suffering. If PC providers neglect the possibility that a patient could foster such an attitude towards suffering they cannot apply proper care. Unintendedly, they might even put the patient under pressure to accept their treatment and therapies. In that way, too, an amplification of suffering could occur.

My analysis falls in line with recent criticisms of PC, focussing on a new medicalisation of dying and on paternalistic tendencies in the care for the dying (Randall and Downie 2006, Bishop 2011). Ostensibly following the leitmotif of individualism, new forms of patronising the patient emerge. Although patient-centeredness is promoted as a core value in the philosophy of PC some patient's wishes and needs obviously remain neglected. However, my considerations come with one caveat, namely that they still lack empirical validation what therefore can be regarded a desideratum. Nonetheless, PC's guiding principle for dealing with suffering needs reflection. If PC providers truly desire to meet the needs of their patients they should take into account that the relief from suffering does not correspond with each and every individual's attitude. Above that, a humbler assessment of the own ambitions, admitting that suffering sometimes resists its alleviation, could open up new, albeit more modest ways of dealing with suffering: enduring it, together with the patient.

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